

2013 Summary Information pertaining to Deaths of Individuals receiving Developmental Disabilities Community-Based Services

When an individual receiving Developmental Disabilities (DD) Community Based services dies, it is expected that the Service Coordinator (SC) is verbally notified immediately. Specialized DD providers report the incident by completing a General Event Report (GER) within Therap. Also, a Notification of Death (NOD) form is due to Developmental Disabilities Central Office (DDCO) within 10 days of the death. If an individual does not have a specialized DD provider, the Service Coordinator is responsible for completion the NOD form. At least quarterly, DDCO Technical Assistance (TA) requests non-certified copies of Certificates of Death from Vital Statistics. Information is gathered from all sources available, minimally: GER, NOD, Certificate of Death, and N-Focus computer system. Other sources of information may include investigations by the DD providers and DD Surveyors.

In the calendar year 2013, DDCO TA received information regarding deaths of forty-seven (47) individuals. DDCO Technical Assistance receives and summarizes information; deaths are included in this summary if the individuals had Service Coordination.

This document is based on information available. The Notification of Death form was changed in May 2013 better identify commonalities among deaths in order to reduce risk of mortality in the future and enhance quality of care and support for the DD population as a whole. Details regarding the new form can be found below. The new form was used for twenty-five (25) deaths, while twenty-one (21) deaths were reported on the version dated 7/2010. This change leads to some of the "unknown" answers reported; the old form did not include some questions on the 5/2013 version. Other "unknown" answers are the result of the provider responding "unknown" to a question, most common when they were not present at the time of death.

Changes to Gathering Information Pertaining to Deaths in 2013

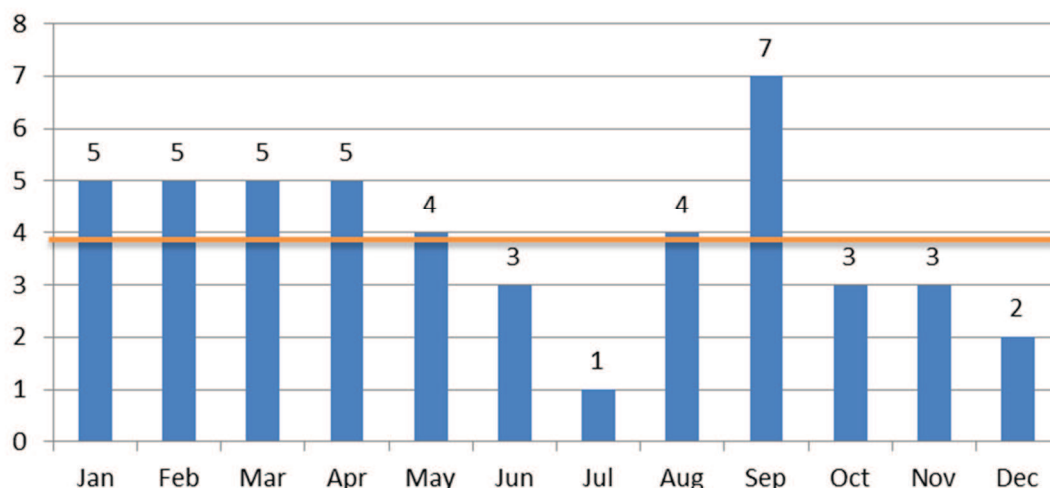
In an effort to gather additional information and delete duplicate requests for information, changes to the NOD included:

- Deleted questions regarding: funding source, request or order for autopsy, primary physician, Protection & Safety, and license or certification of location of death. Added "Was emergency resuscitation (CPR) administered? By whom?"
- Added questions for: significant events in the 30 days preceding death; method of communication; and date and reason for admission when deaths occurred in Nursing Facilities, Hospice Facilities, or Hospitals.
- Changed which medical conditions were listed for Conditions Prior to Death, based on consulting with DDCO Program Specialist RNs.

There is one (1) document pertaining to the forty-seven (47) deaths which DDCO was unable to obtain. The missing Notification of Death form was from a death occurring in March. This individual was served by Mid Nebraska Individual Services. Technical Assistance requested information from the specialized DD provider after the required timeframe passed; no response was received.

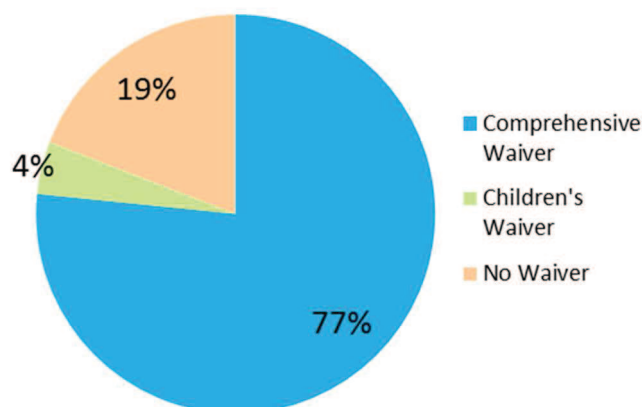
Included are nine (9) individuals who previously resided at Beatrice State Developmental Center (BSDC). These deaths were also comprehensively reviewed by the Columbus Group, a consulting firm under contract to conduct mortality reviews of individuals covered under the contract with the Department of Justice. This group included one (1) individual receiving services in a privately owned ICF-ID, who had the Community-Based oversight of Service Coordination.

Number of Deaths per Month 2013

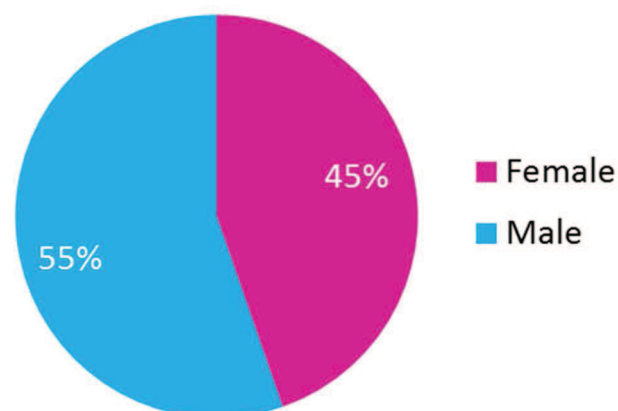


In 2013, there were forty-seven (47) individuals who died while receiving DD service. September had the most deaths, seven (7). July had the fewest deaths, one (1). There was an average of 3.916 deaths per month.

2013 Summary Information Pertaining to Deaths of Individuals Receiving Developmental Disabilities Community-Based Services

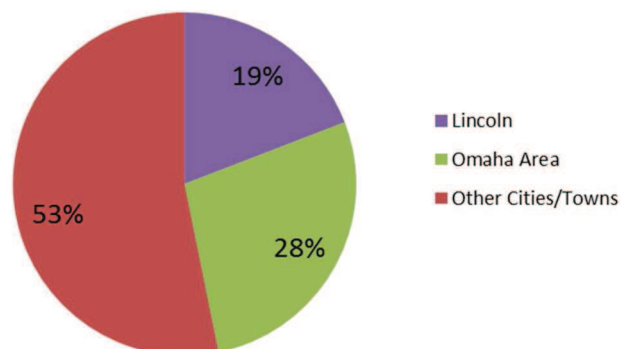
Funding Source

Thirty-eight individuals (81%) were on a DD Medicaid Waiver: thirty-six (77%) on Comprehensive (DDAC), two (4%) on Children's (CDD). Of the nine individuals (19%) without Waiver status (DDAID): eight (17%) were receiving State Aid, seven of which (15%) were Service Coordination only; one individual (2%) paid for services privately. No one who died was on the Day Waiver (DDAD).

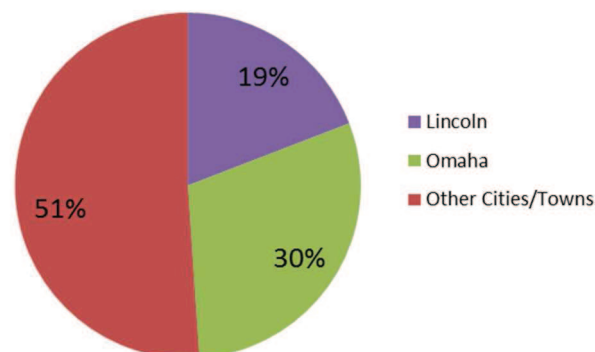
Gender

Twenty-one females (46%) and twenty-six males (55%) died.

In 2013, DDCO began asking about Method of Communication. Method of Communication is available for thirty-seven (37) of the deaths which occurred in 2013. Ten (21%) were unavailable due to using the previous version of the form. For the individuals whose information is available: twenty-seven (27) were verbal, English (57%) and ten (10) were non-verbal (21%). In future reviews this information will be reported alongside the data for illness and health care prior to death, as the question intent is whether person is able to communicate their need for medical attention.

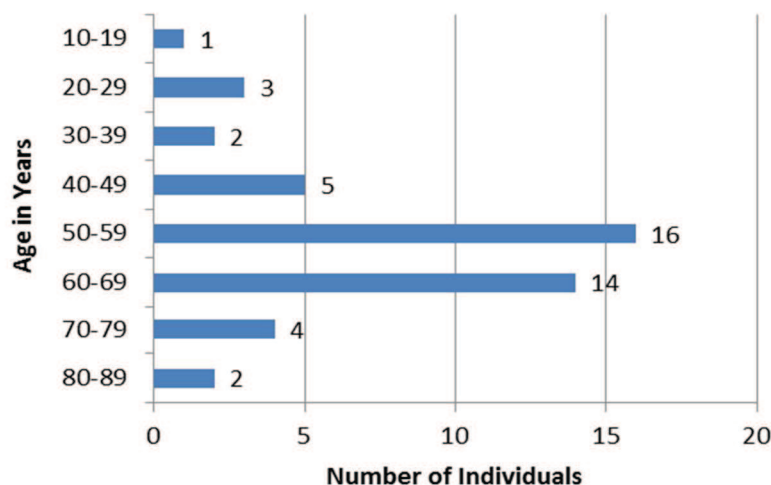
Community Where Individual Lived

Prior to death, nine (19%) individuals lived in Lincoln, twelve (26%) in Omaha proper, one (2%) in an Omaha suburb, and twenty-five (53%) in other locations across the state.

Community Where Death Occurred

Twenty-three of the forty-seven deaths (49%) occurred in Lincoln or Omaha: nine (19%) in Lincoln and fourteen (30%) in Omaha. All Omaha deaths occurred in Omaha proper. Twenty-four deaths (51%) occurred in other locations across the state.

2013 Age at Death

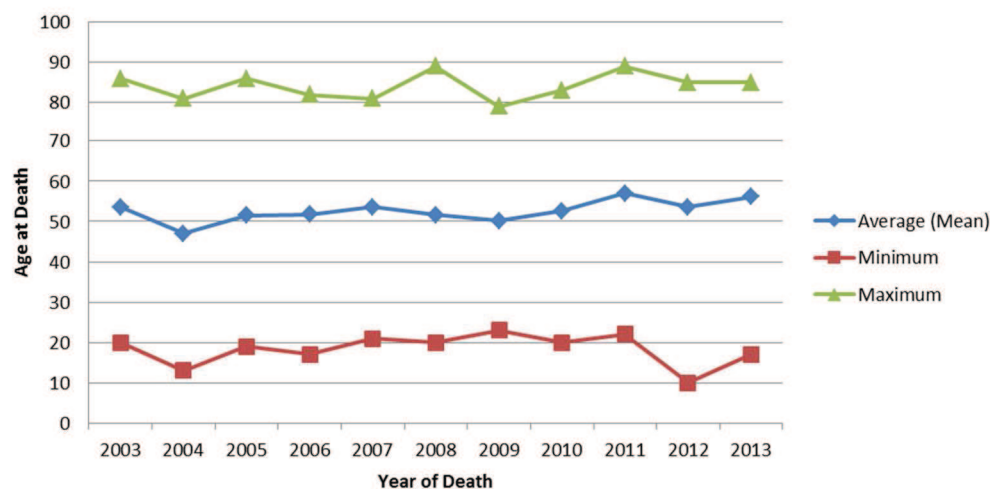


Average Age at Death was 56.128 years old. The youngest person was 17 years old; the oldest 85 years old. Sixteen (16) individuals who died (34% of deaths) were in their fifties. The mortality rate for individuals receiving Community Based DD services from a specialized provider in 2013 was 10.8; see chart "Number of Deaths and Mortality Rates for DD Specialized Providers in Nebraska" within this document.

According to the World Life Expectancy, the most recently available numbers list the national average age at death in the United States as 78.7 years and the Nebraska average age at death as 79.2 years.

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), in 2010, the most recently available year, the average age at death for individuals with ID/DD was 67 for women, 63 for men, and 65 overall.

Time Trend Graph: Age at Death



Time Trend: Age at Death for Individuals with DD Community Based Services in Nebraska

Year	Average Age (Mean)	Median Age (Midpoint)	Mode (Most Frequent)	Minimum Age	Maximum Age	Number of Deaths
2013	56.128	58	65	17	85	47
2012	53.632	55	50	10	85	57
2011	57	58.5	62	22	89	36
2010	52.657	51	51	20	83	37
2009	50.179	50	49	23	79	46
2008	51.641	51	51	20	89	42
2007	53.595	55	54	21	81	42
2006	51.7	52	52	17	82	45
2005	51.536	50	48	19	86	41
2004	47.026	47	55	13	81	36
2003	53.553	51	39	20	86	47

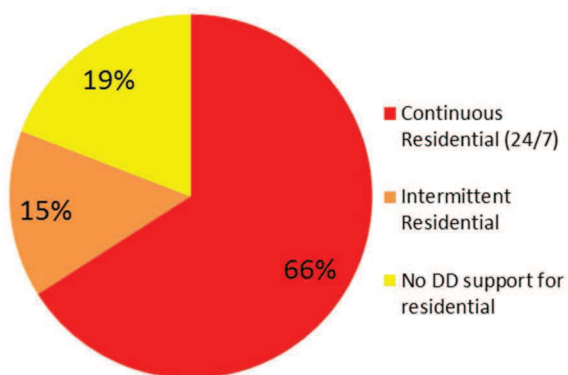
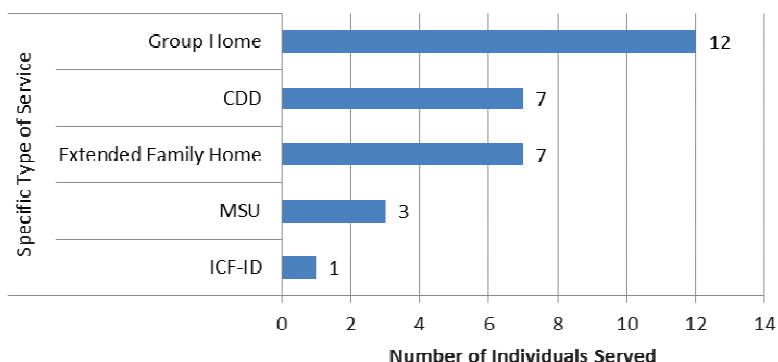
Number of Deaths and Mortality Rates for DD Specialized Providers in Nebraska

Specialized DD Provider	Number of Deaths in 2013	Number of Individuals Served	Mortality Rate*
Mosaic	7	483	14.49
Region V	6	896	6.69
Region VI—ENCOR	5	732	6.83
Region II—SCDS & SWATS	4	114	35.08
Region I—Office of Human Development (OHD)	3	160	18.75
Mid Nebraska Individual Services (MNIS)	3	300	10.00
Vodec	3	289	10.38
Community Alternatives Nebraska (CAN)	1	140	7.14
Developmental Services of Nebraska (DSN)	1	207	4.83
Home at Last	1	16	62.50
Integrated Life Choices (ILC)	1	207	4.83
NorthStar	1	282	3.54
OMNI Behavioral Health	1	27	37.03
Prime Home DDS	1	33	30.30
No Specialized Service Provider	9		
Grand Total (all individuals in DD services, not just served by providers who reported deaths)	47	4664	Overall Statewide Rate 10.08

*Number of Deaths per 1,000 People. For comparison, the overall Mortality Rate in the United States in 2012 was 8.39, per CIA Word Factbook.

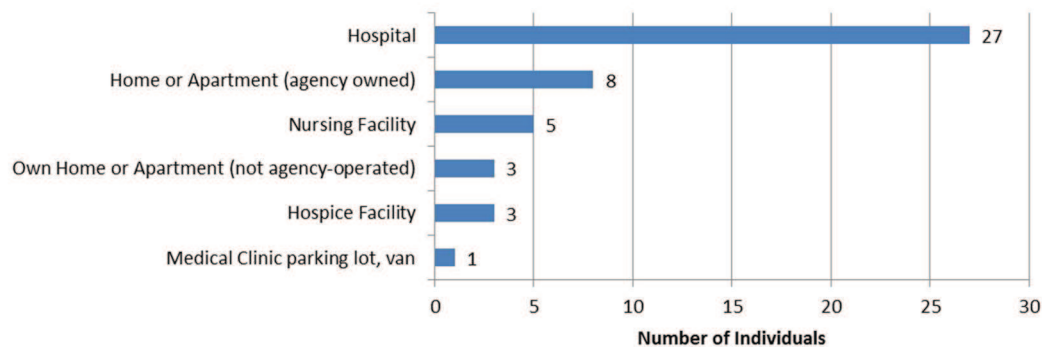
Thirty-eight (38) individuals had a specialized DD provider, two (2) had non-specialized providers (including one who also had a specialized provider), and eight (8) were Service Coordination only. Table includes specialized providers who served individuals who died in 2013. If an individual received services from multiple providers the one listed is the one with the most funding designated.

Fourteen (14) Specialized DD providers reported deaths in 2013. Mosaic provided services to the largest number of individuals who died, seven (7). Home at Last had the largest Mortality Rate at 62.50 though they only had one death; this is due to them currently serving sixteen (16) individuals.

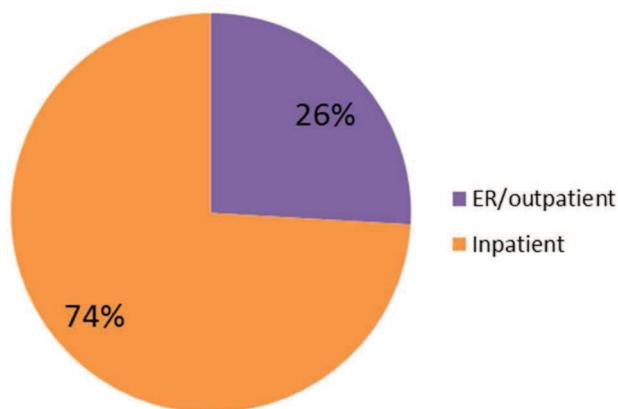
Type of Residential Services**Type of Continuous Residential (24/7)**

The individuals who died lived in a variety of residences, though thirty-one (31) of forty-seven individuals (66%) resided in continuous residential settings, with staff available 24/7: seven (7) in Extended Family Homes (EFHs), seven (7) in Centers for the Developmentally Disabled (CDDs), three (3) in medical support units (MSUs), one (1) in ICF-ID, one (1) in their own home or apartment, and the remaining twelve (12) were in group homes not otherwise categorized. Seven (7) individuals (15%) received intermittent DD services: two (2) in their family home, four (4) in their own home or apartment, and one (1) in a nursing facility (NF). Nine (9) individuals (19%) lived without DD residential services: four (4) individuals lived in nursing facilities, two (2) with roommates, one (1) in hospice facility, one (1) in family home, and one (1) in Adult Family Home (AFH).

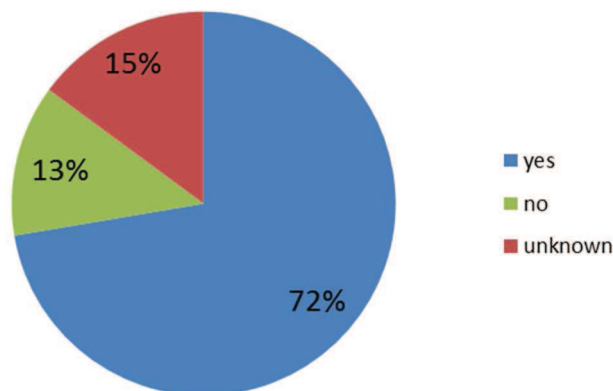
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Location at Time of Death

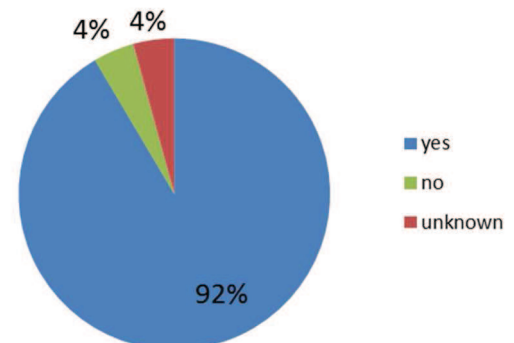
Location of death occurred in a variety of places; twenty-seven of forty-seven (57%) died in hospitals. Since this is the most frequent location of death, generally remaining at or above half of all deaths, DDCO further categorized hospital deaths occurring in 2013 as: Inpatient, ER/Outpatient, and DOA; this information was gathered from the State of Nebraska Certificate of Death. Five deaths (11%) occurred in nursing facilities. Three deaths (6%) occurred in hospice facilities.

Deaths Occurring in Hospitals

Year	Percentage of Deaths Occurring in Hospitals
2013	57%
2012	51%
2011	47%
2010	54%
2009	59%
2008	64%
2007	67%
2006	58%
2005	59%
2004	53%
2003	55%

Illness in 72 hrs. Prior to Death

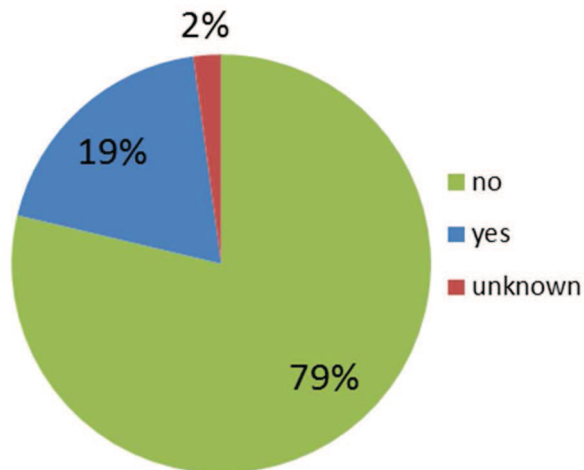
Thirty-four individuals (72%), including those on hospice, were reported to be ill in the 72 hours preceding death. Six (13%) were reported to not be ill, and health level was unknown for seven individuals (15%).

Healthcare Treatment in 30 Days Prior to Death

Forty-three individuals (92%) received treatment by a healthcare provider within 30 days of death; this includes treatment received immediately before death. Two individuals (4%) did not receive treatment, and information was unknown regarding two deaths (4%).

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Hospice Services

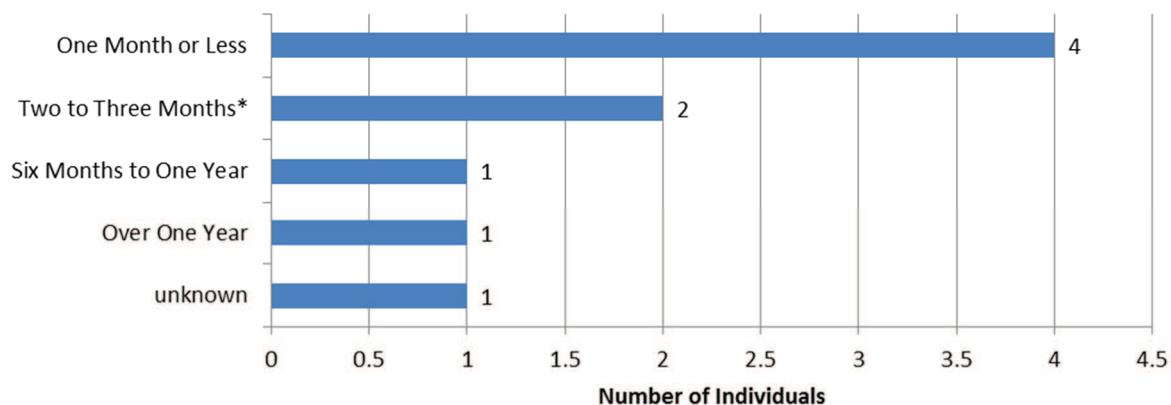


Nine of forty-seven individuals (19%) were known to be receiving hospice services, thirty-seven (79%) were not, and we were unable to determine hospice status for one death (2%).

Those on hospice ranged in age from 50-70. The average length of time on hospice was 93 days, though the most people (4 individuals) were on hospice for one month or less.

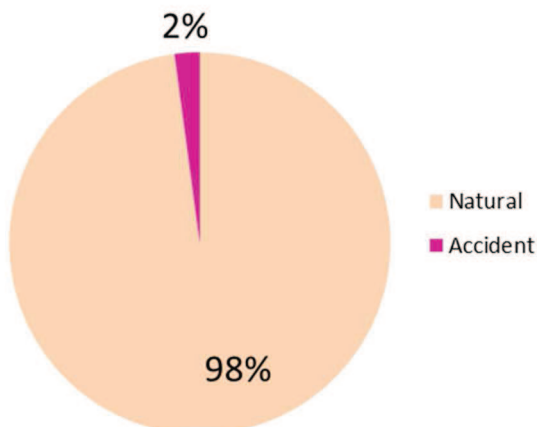
Per National Hospice & Palliative Care Organization, in 2010, the most recently available year, 42% of deaths in the United States involve hospice; in 2011 the average length of time for someone on hospice was seventy-two (72) days, and 17% of people receiving hospice are under age sixty-five (65).

Length of Time on Hospice



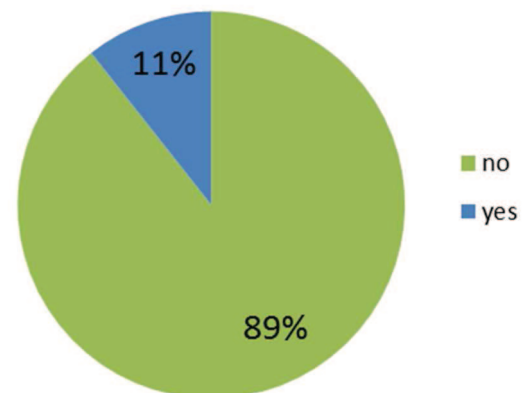
*Note no Three to Six Months timeframe.

Manner of Death



Forty-six deaths (98%) were determined to be Natural while one (2%) was ruled Accidental. There were no deaths that were determined to be suicide or homicide. This information comes from the Certificates of Death.

Autopsy Completed



The Death Certificate indicates if an autopsy was completed and if findings were available to complete the Cause of Death section. Five autopsies (11%) were completed. No autopsy reports were requested or received by DDCO.

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NODs ask about Prior Existing Conditions via check boxes for specific conditions, some with additional checkboxes or blank space for specificity or details. The list of conditions was developed with input from the Division RNs.

Condition	Number of Individuals	Percentage of Deaths
Alzheimer's / Dementia	3	6%
Bowel Obstruction (history of)	6	13%
Cancer	9	19%
Cardiac:		
Congestive Heart Failure (CHF)	6	13%
Coronary Artery Disease (CAD)	5	11%
Hypertension	11	23%
Hypotension	2	4%
Deep Vein Thrombosis (DVT)	1	2%
Myocardial Infarction	0	-
Drug Toxicity:		
Elevated med levels in blood	0	-
Substance abuse (history of)	0	-
Renal:		
Diabetes	6	13%
Dialysis	0	-
Kidney Disease	3	6%
Respiratory:		
Asthma	4	9%
Chronic Obstructive Pulmonary Disease (COPD)	5	11%
Oxygen Dependency	6	13%
Pulmonary Embolism (lung clot)	6	13%
Pneumonia, aspiration	4	9%
Pneumonia, community acquired	9	19%
Smoking (history of)	1	2%
Swallowing Disorder / Dysphagia	11	23%
Tracheostomy	3	6%
Seizures	16	34%
Sepsis	2	4%
Suicide Attempt (history of)	0	-

In May, the Notification of Death form began asking about activities occurring within 30 days prior to death via check boxes for specific situations causing increase to risk. The list of conditions was developed with input from the Division RNs.

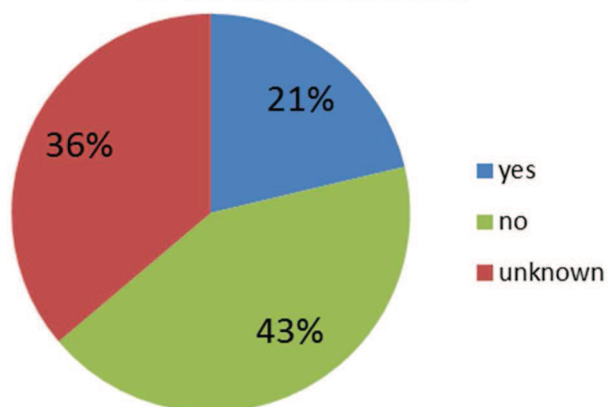
Activity	Number of Individuals	Percentage of Deaths
Aspiration	6	13%
Cellulitis or Decubitus Ulcer	2	4%
Choking Incident	1	2%
Emergency Safety Intervention (physical hold)	1	2%
Fall	8	17%
Infectious or Communicable Disease	0	-
Medication Error	2	4%
Surgical Procedure	2	4%

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Causes of Death		
Category	Specific	Number of Individuals
Respiratory	Aspiration, Aspiration Pneumonia (2), Bilateral Pneumonia, Bronchopneumonia—Aspiration, COPD, Pneumonia (3), Respiratory Failure (3), Septic Aspiration Pneumonia	13
Cardiac	Cardiac Arrest (2), Cardiac Arrhythmia (2), Cardiomyopathy, Cardiopulmonary Arrest, Congestive Heart Failure (2), Heart Disease, Myocardial Infarction, Myocardium Hypertrophy, Sudden Cardiac Arrhythmia, Systolic Congestive Heart Failure	14
Sepsis	Sepsis (2), Septic Shock	3
Cancer	Colon Cancer, Lung Cancer (2), Metastatic Breast Cancer, Oral Cavity Cancer, Pancreatic Cancer	6
Dementia/Alzheimer's	Dementia (2)	2
Other	Bowel Obstruction, Bowel Perforation, Complications of Cerebral Palsy, Ischemic Bowel, Myotonia, Status Epilepticus, Thromboembolic Event	7
Undetermined or Unspecified		2

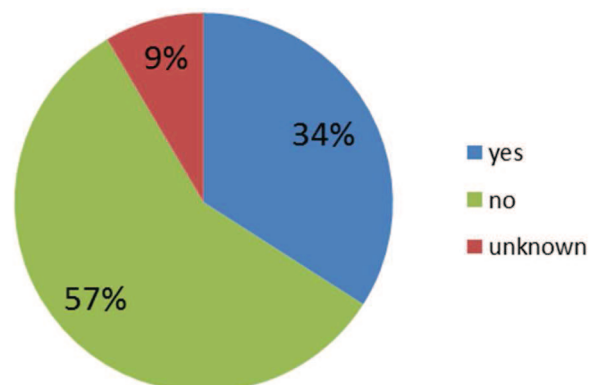
DDCO does not have a medical professional review Death Certificates or other information in order to categorize deaths (i.e. heart failure, cancer). Categories were provided by DDCO Program Specialist RNs and TA used these to categorize the “cause of death” listed on the Certificate of Death.

CPR Administered



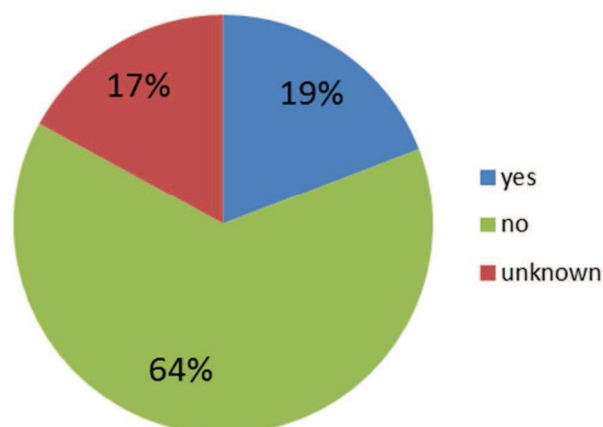
There were at least ten cases (31%) of CPR being administered, twenty deaths (43%) did not involve CPR, and information is unknown for seventeen deaths (36%). We did not track who administered CPR when given.

Call to Emergency Services (911)

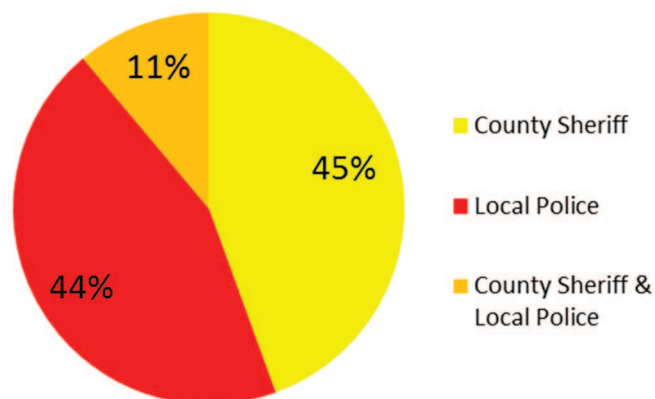


For at least sixteen individuals (34%) emergency services were requested (call to 911). Twenty-seven deaths (57%) did not involve a 911 call. Information is unknown in four deaths (9%).

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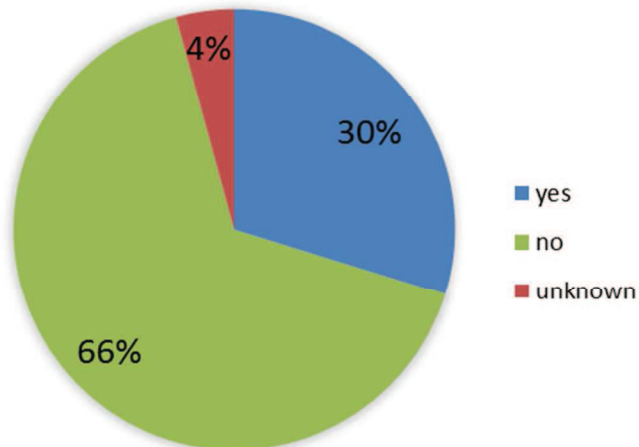
Call to Law Enforcement

Law enforcement was called regarding nine deaths (19%); law enforcement was not called regarding thirty deaths (64%) and information is unknown in eight cases (17%). According to provider report, three deaths (6%) were being investigated by the law enforcement agency that was called; DDCO does not have access to law enforcement investigations.

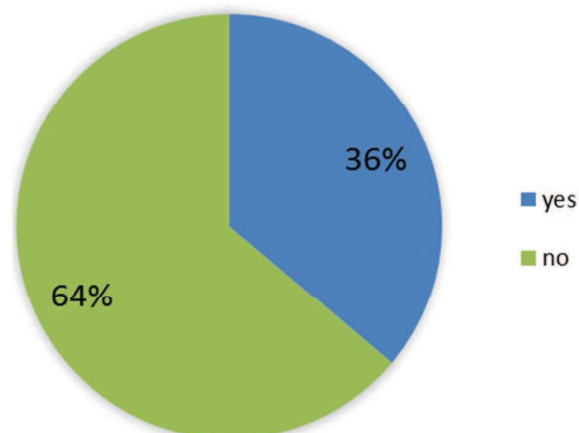
Type of Law Enforcement Called

For the nine deaths (19%) where law enforcement was called, the following agencies were called:

County Sheriff – 4 times (45%)
 Local Police – 4 times (44%)
 County Sheriff & Local Police – 1 time (11%)

DD Provider Investigation

DD providers conducted internal investigations in fourteen (14) cases (30%), thirty-one (31) had no provider investigation (66%), and this was unknown in two (2) cases (4%). Three of fourteen (21%) provider investigations have been received by DDCO; this is not currently requested from provider agencies.

DD Surveyor Review

DD Surveyors reviewed seventeen (17) complaints regarding deaths (36%). These reviews led to three (3) incidents of DD providers being out of regulatory requirements and receiving citations. Thirty (30) deaths were not reviewed (64%).

There were no APS/CPS intakes due to deaths. No individuals who died had incidents of abuse or neglect investigated by Protection and Safety within the last year of their life.